

Who is infected with HIV but does not yet know? Detailed data tables and technical notes

Technical Notes:

The U.S. Centers for Disease Control and Prevention (CDC) estimates that about one-quarter of HIV infected persons nationwide do not know they are infected¹ (previous editions of the Epidemiologic Profile estimated that about one-third of HIV-infected persons either did not know they were infected or were not in care in Massachusetts). People unaware of their status do not access HIV-related care and treatment, and therefore, are unable to experience the benefits of these services, including improved health, better quality of life and longer survival. Additionally, they lack the opportunity to be counseled regarding further prevention of HIV transmission. Applying the national estimate to the number of people living with HIV/AIDS in Massachusetts reported to the HIV/AIDS Surveillance Program (N = 15,289 on December 31, 2004), and adjusting for completeness of reporting, would yield an estimated 5,996 people who are infected with HIV and do not know it, and an additional 2,698 people who know their status but have not been reported. Therefore, the estimated total number of people currently living with HIV/AIDS in Massachusetts, including people known to the system as well as those yet to be identified, is in the range of 23,000 – 25,000 people.

People who are first diagnosed with HIV infection (that they may have been unaware of) at the same time that they are diagnosed with AIDS are considered “concurrently diagnosed”. In the data that follow, a person is considered to have been concurrently diagnosed with HIV infection and AIDS if both the initial diagnosis of HIV infection and AIDS occurred within two months. The profile of people who are concurrently diagnosed with HIV infection and AIDS highlights a population of people who may have first learned about their HIV infection status late in the progression of HIV disease. It is likely that people who are concurrently diagnosed with HIV and AIDS have been infected for more time prior to learning their HIV status than people who learn of their status longer before being diagnosed with AIDS. As such, the profile of people who are concurrently diagnosed with HIV infection and AIDS provides an approximation of people who are infected but do not yet know. This group is one of the target populations for HIV counseling and testing efforts.

When using these data, one must keep in mind the confounding effects of place of birth. People born outside the US may have learned of their HIV status in their native country and then moved to Massachusetts (or elsewhere in the US) to receive care; as opposed to moving to Massachusetts, becoming infected with HIV and then learning about their HIV status late in the course of HIV disease. There is no way to differentiate between these two scenarios from HIV surveillance data, although the latter represents a missed opportunity for Massachusetts care providers and the former may not. When reviewing

¹ Fleming PL, Byers RH, Sweeney PA, Daniels D, Karon JM, Janssen RS. HIV prevalence in the United States, 2000. Abstract 11. 9th Conference on Retroviruses and Opportunistic Infections, Seattle, Washington, February 24-28, 2002

the proportion of concurrent diagnoses by race/ethnicity one should note the differences in the distribution of place of birth by race/ethnicity. Fifty-nine percent of black individuals concurrently diagnosed with HIV infection and AIDS within the three-year period 2002 to 2004 were non-US born compared to 37% of Hispanic individuals and 10% of white individuals.

Table 1. People diagnosed with HIV infection and AIDS within two months and all people diagnosed with HIV infection by gender, race/ethnicity, and mode of exposure: Massachusetts, 2002 – 2004

	HIV and AIDS diagnosed within 2 months	All HIV infection diagnoses	% diagnosed with HIV and AIDS within 2 months
Gender:	N	N	%
Male	562	1,913	29%
Female	223	857	26%
Race/Ethnicity:	N	N	%
White (non-Hispanic)	272	1,079	25%
Black (non-Hispanic)	307	906	34%
Hispanic	193	696	28%
Asian/Pacific Islander	13	46	28%
Amer. Indian/Alaska Native	0	4	0%
Exposure Mode:	N	N	%
Male-to-male sex (MSM)	201	884	23%
Injection Drug Use (IDU)	115	441	26%
MSM/IDU	9	57	16%
Heterosexual Sex	109	347	31%
Other ²	6	36	17%
Total Undetermined	345	1,005	34%
• Pres. heterosexual sex ³	230	642	36%
• Undetermined ⁴	115	363	32%
TOTAL⁵	785	2,770	28%

¹ Percentages calculated from a denominator and numerator of less than 5 are unstable and therefore not presented

² Other includes pediatric and blood/blood products

³ Unknown risk of partner

⁴ Includes those still being followed up for risk information, those who have died with no determined risk, and those lost to follow-up

⁵ Totals include people of unspecified race/ethnicity

Data Source: MDPH HIV/AIDS Surveillance Program, Data as of 7/1/05

Note: The category of “presumed heterosexual” is used in Massachusetts to re-assign people who are reported with no identified risk but who are known not to have reported any other risks except heterosexual sex with a partner of unknown HIV status or risk. Massachusetts uses this category to distinguish these cases from other undetermined cases about which we know less. Nationally, the Centers for Disease Control and Prevention categorizes “presumed heterosexual” cases as “no identified risk”. As such, comparisons of the presumed heterosexual category cannot be made to national data. Caution should be used in interpreting data for presumed heterosexual, as it is still not clear what the exposure risk is for people in this category. Although a person may not report other risk behaviors such as injection drug use or male-to-male sex to his/her health care provider, it does not necessarily mean that he/she has not engaged in them. There are many barriers to disclosing HIV risk behaviors in the health care setting such as a limited patient-provider relationship or stigma.

Table 2. People diagnosed with HIV infection and AIDS within two months and all people diagnosed with HIV infection by place of birth and age at HIV/AIDS concurrent diagnosis and HIV diagnosis: Massachusetts, 2002 – 2004

	HIV and AIDS diagnosed within 2 months	All HIV infection diagnoses	% diagnosed with HIV and AIDS within 2 months
Place of birth:	N	N	%
US	422	1,711	25%
Puerto Rico and other US Dependencies ¹	74	274	27%
Non-US	289	785	37%
Age at diagnosis:	N	N	%
0-12	1	25	4%
13-19	6	47	13%
20-24	32	178	18%
25-29	75	295	25%
30-34	115	462	25%
35-39	154	577	27%
40-44	146	493	30%
45-49	107	331	32%
50+	149	362	41%
TOTAL	785	2,770	28%

¹ Ninety-three percent of people diagnosed with HIV infection from 2002-2004 who were born in a US dependency were born in Puerto Rico and 7% were born in an unknown US dependency

² Percentages calculated from a denominator and numerator of less than 5 are unstable and therefore not presented
Data Source: MDPH HIV/AIDS Surveillance Program, Data as of 7/1/05

Table 3. People diagnosed with HIV infection and AIDS within two months and all people diagnosed with HIV infection by gender and race/ethnicity: Massachusetts, 2002 – 2004

	HIV and AIDS diagnosed within 2 months	All HIV infection diagnoses	% diagnosed with HIV and AIDS within 2 months
Males by race/ethnicity:	N	N	%
White (non-Hispanic)	237	913	26%
Black (non-Hispanic)	179	491	36%
Hispanic	139	455	31%
Asian/Pacific Islander	7	31	23%
Total Male¹	562	1,913	29%
Females by race/ethnicity:	N	N	%
White (non-Hispanic)	35	166	21%
Black (non-Hispanic)	128	415	31%
Hispanic	54	241	22%
Asian/Pacific Islander	6	15	40%
Total Female¹	223	857	26%
¹ Totals include American Indian/Alaska Native and people of unspecified race/ethnicity Data Source: MDPH HIV/AIDS Surveillance Program, Data as of 7/1/05			